



Risk factors for patient-reported errors during cancer follow-up: Results from a national survey in Denmark



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ABSTRACT

Due to an increased cancer survival, more cancer patients are referred to follow-up after primary treatment. Knowledge of patient safety during follow-up is sparse.

Objective: To examine patient-reported errors during cancer follow-up and identify factors associated with errors.

Design: A national survey on cancer patients' experiences of treatment and aftercare was conducted in 2012, about two years following cancer diagnosis (N=6914). Associations between patient-reported errors during follow-up and covariates were examined using multiple logistic regression. Qualitative responses were analysed using text analysis.

Results: This study included 3731 patients, representing a response rate of 64%. Overall, 27.6% of patients reported at least one error during cancer follow-up. 11.7% reported that important information was missing at follow-up consultations; 9.8% were not called in for a follow-up as expected; 16.7% reported that the doctor/nurse handling the follow-up consultation were ill-prepared on their course of disease. Other errors were reported by 4.7%. Patients who reported errors in follow-up were more likely to report an error or complication during primary cancer treatment, not having one health professional with oversight and responsibility for their overall follow-up pathway, be younger, have a diagnosis of rare cancer, poorer self-rated health and high usage of healthcare services.

Conclusion: Workflows related to handling of test results, referrals, bookings and medical records have to be improved. Introduction of one particular healthcare professional responsible for the patients' follow-up may result in fewer patient-reported errors however interventions are needed to examine this. Patients prone to errors should be subject to particular attention.

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1. Introduction

Every year 35,000 new cancer patients are diagnosed and currently nearly 267,500 persons are living with a cancer diagnosis in Denmark [1]. Due to an increased cancer survival, more cancer patients are followed-up after completing primary treatment. The follow-up usually involves outpatient consultations by specialists at the hospital with the aim to control for recurrence or metastasis, provide information and psychosocial support [2].

Cancer survivors are said to be lost in the transition from patient to survivor due to a fragmented and poorly coordinated cancer care

system and the absence of a locus of responsibility for follow-up care [3].

Previous studies on safety and quality in cancer care show that due to the severity of cancer disease and the hazardous treatment, cancer patients are at particular risk of adverse events [4–8]. 11% of patients report being very concerned about their safety [9]. Studies on cancer patient safety have mainly focused on treatment. Thus, knowledge of patient safety during follow-up is sparse [10].

Follow-up care in Denmark involves multiple care providers and care settings, and patients rarely meet the same doctor at every appointment. This potentially increases the risk of errors as many errors are associated with inadequate care transitions and multiple contacts [4,8,11–13].

Usually, safety is assessed from a healthcare perspective and the patients' experiences of errors have only been explored to a limited extent. However, gathering information from various sources is necessary to improve the understanding of hazards [6,14,15].

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¹ At the time when the study was accomplished.

Patients are usually vigilant observers of the care they receive; they have a unique knowledge of their own cancer pathway and can provide information about experienced errors and safety-related processes [14,16]. Studies indicate that age [13,15,17,18], educational level [17,19], health status [13,17,19,20], clinical complexity [18] and comorbidity [18] are all associated with patients' reporting of errors during hospitalisation and ambulatory care.

2. Material and methods

To explore the patients' perspectives on the care and safety delivered during cancer treatment and follow-up, the Danish Cancer Society conducted a nationwide cross-sectional survey. Based on elements of the survey this study aims to examine patient-reported experience of errors during cancer follow-up and to identify patient-, organisational- and treatment related factors associated with errors. The definition of adverse events is unintended or unexpected incidents, which could have, or did harm the patient. The term *error* was chosen instead of e.g. 'adverse event' because the cognitive validation showed that patients understood the term error and used it to describe rather serious problems, whereas minor problems in general were not considered errors. Thus, we consider the patient-reported errors to be errors, even though some of the described errors mostly go beyond 'service complaints' or relates to expectations about quality that are not met.

2.1. Setting

The Danish healthcare system is primarily publicly funded with free access to diagnostics, treatment and follow-up for all citizens.

2.2. Study population

All patients registered with cancer for the first time in The Danish National Patient Register [21] from April 16th to September 15th 2010, alive by 4 June 2012 and aged ≥ 18 was sent a questionnaire including a prepaid envelope, two to 2.5 years following their cancer diagnosis (N = 6914). After three weeks, non-responders received a reminder. 4401 patients returned the questionnaire (response rate 64%).

This study is based on a subpopulation of the national survey, that is patients who reported being to at least one follow-up consultation and replied to at least one of the questions on errors in follow-up care listed in the questionnaire (n = 3731, 84.8% of responders). Thus, the patients reported the errors in their survivorship phase, not during active treatment.

2.3. Development of questionnaire

A review of the literature and six focus group interviews were conducted to identify important aspects of quality and safety during cancer treatment and survivorship. The questionnaire contained 121 items in total. It was validated through 14 cognitive interviews with patients [22].

2.4. Variables

Errors during follow-up were recorded by asking patients if they experienced one or more of the following situations in connection with their follow-up consultations (answer: No; Yes, a single time; Yes, more times; Don't know/not relevant):

- Important information about the course of my disease (e.g. records, letters or test results) was missing when I attended a follow-up consultation

- I was not called in for a follow-up consultation as expected
- The doctor/nurse handling my follow-up consultation were ill-prepared on my course of disease.

These three closed questions on errors were drafted based on previous patient safety studies [5,6]. They were posed to quantify 'known' types of error. Also patients were asked if they had experienced "other errors" than the ones stated (no/yes), and were given the opportunity to describe the error.

The analysis of factors associated with error-reporting included three areas:

- *The patient*: sex; age; education; cancer-type; comorbidity; self-rated health.
- *Organisational settings and care transitions*: setting for follow-up consultation; contacts to hospital; contacts to different health-care providers; one health professional with oversight and responsibility for the overall follow-up pathway.
- *Primary cancer treatment*: if the patient had experienced an error or complication during primary treatment.

Information on the patient's age, sex and cancer type were retrieved from The Danish National Patient Register. The remaining information were patient-reported.

Cancer types were grouped into three categories reflecting the incidences in Denmark (common, less common, rare). We defined comorbidity as the presence of one or more chronic diseases in addition to cancer. Patients reported self-rated health on a seven-point Likert scale.

High usage of healthcare services is a proxy of care transitions. Thus, this was analysed by number of contacts to hospital, and by creating a variable that combined contacts (yes/no) to nine different types of providers (e.g. hospital, GP, home nurse, pain clinic).

Patient-reported error or complication during primary treatment were combined in the analysis and considered an indicator of previous error. This variable comprised three questions on primary treatment at hospital: 1) complication(s) in surgery (e.g. infection, thrombosis) 2) important information about the course of disease was missing when attending a consultation/treatment, 3) not called in for a consultation/treatment as expected.

2.5. Data analyses

We estimated a multivariate logistic regression model for each of the three specific errors and one for 'all errors' which combined the three specific errors and the question on other errors. The outcome was error(s) during follow-up. For all models, a likelihood ratio test for significance testing was conducted; p-value ≤ 0.05 was considered statistically significant. To begin with, the models included all the covariates that had a p-value ≤ 0.1 in the univariate analyses. To get to the final models, covariates were withdrawn one by one starting with the ones least significant. We conducted a Test for trend across the values of certain covariates, e.g. age. The results presented are unadjusted and adjusted Odds Ratios (OR) with 95% confidence intervals (CI).

An analysis of non-responders was conducted to investigate whether non-responders on the four questions on errors were different from responders. Analyses of non-responders of the entire national survey has been published elsewhere [2]. Statistical analyses were performed using SAS 9.3.

The open-ended question on 'other errors' were analysed using systematic text condensation. Thus, we created categories of types of errors until no more categories emerged. All errors underwent a deductive coding according to the created categories. An expert in patient safety conducted the coding and analysis. Some of the

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